The rising tide of dementia deaths: triangulation of data from three routine data sources using the Clinical Practice Research Datalink

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Abstract

Background

Dementia is currently the leading certified underlying cause of death in England. We assess how dementia recording on Office for National Statistics death certificates (ONS) corresponded to recording in general practice records (GP) and Hospital Episode Statistics (HES).

Methods

Retrospective study of deaths (2001-15) in 153 English General Practices contributing to the Clinical Practice Research Datalink, with linked ONS and HES records.

Results

Of 207,068 total deaths from any cause, 19,627 mentioned dementia on the death certificate with 10,253 as underlying cause; steady increases occurred from 2001 to 2015 (any mention 5.3% to 15.4%, underlying cause 2.7% to 10%). Including all data sources, recording of any dementia increased from 13.2% to 28.6%. In 2015, only 53.8% of people dying with dementia had dementia recorded on their death certificates. Among deaths mentioning dementia on the death certificate, the recording of a prior diagnosis of dementia in GP and HES rose markedly over the same

period. In 2001, only 76.3% had a prior diagnosis in GP and/or HES records; by 2015 this had risen to 95.7%. However, over the same period the percentage of all deaths with dementia recorded in GP or HES but not mentioned on the death certificate rose from 7.9% to 13.3%.

Conclusions

Dementia recording in all data sources increased between 2001 and 2015. By 2015 the vast majority of deaths mentioning dementia had supporting evidence in primary and/or secondary care. However, death certificates were still providing an inadequate picture of the number of people dying with dementia.

Keywords

Dementia, Mortality, Death certificates, Cause of death, Primary care

Background

Dementia is defined as the progressive, irreversible loss of cognitive functioning, usually occurring after age 65 years and encompassing many different subtypes, of which Alzheimer's is the commonest[1]. Although no gold standard exists for dementia ascertainment[2] an estimated 850,000 people in the UK are living with dementia[1], a significant burden for health and social care systems.

Dementia is now the most commonly certified underlying cause of death in England according to Office for National Statistics (ONS) figures, accounting for 12.7% of all registered deaths in 2017[3]. It has overtaken cardiovascular causes as the leading underlying cause of death in the UK. ONS data suggests that death rates from dementia are steadily increasing in all older age groups (>65 years) and in both males and females, but studies suggest that the age-specific incidence rates of dementia have fallen over the last two decades, driven primarily by a reduction of dementia diagnoses in men[4].

There has been increased public awareness of dementia due to Government initiatives such as the National Dementia Strategy[5] and the Prime Minister's Challenge on Dementia 2020[6]. This was associated with incentivising primary care to record dementia diagnosis in the Quality and Outcomes Framework (QOF)[7], and dementia-related Read code changes introduced after 2006[8]. There were high national general practice participation rates in the dementia care incentive schemes of Directed Enhanced Services 18 (DES18) and Dementia Identification Scheme (DIS) of

98.5% and 76% respectively[9]. In 2012 the Department of Health also introduced incentives to increase dementia diagnosis in secondary care, by case finding in older inpatients[8].

The aim of this work is to assess how well dementia recording in death certification relates to both routine recording in electronic general practice records and Hospital Episode Statistics (HES) over the period 2001 to 2015. The study period was chosen as it coincided with the introduction of the latest version of the International Classification of Diseases 10th revision (ICD-10)[11], so codes relating to dementia were consistent over time and in addition to showing increases in dementia death rates, it also included key policy changes to QOF[8] and hospital recording[12].

Methods

This study used data from the Clinical Practice Research Datalink (CPRD GOLD), a national validated database of patient records collected during routine general practice consultations. Diagnoses are recorded on the system using a hierarchical clinical classification system called Read codes[13], either by staff at the time or from other sources such as discharge data from hospitals. As of 2015, CPRD had about 700 practices nationally which had contributed data (~7% of the UK population), and the registered patients have been shown to be broadly representative of the UK population terms of age, sex and ethnicity[14]. The pseudo-anonymised information

from this primary care database is linked to external data (HES and ONS) via an independent trusted third-party[15]. HES is a data source recording every NHS hospital admission in England containing information on clinical diagnoses[16]. ONS data include details from the death certificate for both the underlying cause of death and all causes mentioned on the death certificate. ONS death certificate data were linked to GP records via a unique patient identification number using a linkage algorithm while HES data were linked in a series of deterministic linkage steps[15].

Study Sample

In order that findings reflect trends over time, rather than differences due to practices entering and exiting CPRD over time, we restricted our study to 153 English practices that contributed up-to-standard data over the entire study period 2001 to 2015. One of the criteria for this quality control measure carried out by CPRD is number of recorded deaths within a practice[17]. Additionally, the study was restricted to English practices as patients residing outside England are not linked to ONS mortality data or HES within CPRD[14].

All deaths over the period 2001-2015 were identified from the electronic General Practice (GP) records and then linked to ONS mortality to confirm the death. There is near agreement between the two sources, with 98.2% of deaths in ONS reported to be also identified in CPRD[18]. However, it is common for the CPRD date associated with the death to be on average 1 month later, so we used the ONS date for the date of death in our analyses. Codes for dementia of any type were identified within each

of the GP, HES and ONS datasets. A patient was defined as having "died with dementia" if they had any evidence of a diagnosis of dementia on any of the three data sources.

Dementia recording on GP electronic records

Within the patient's primary care record we searched for diagnoses of dementia ("GP diagnosis") using specific Read codes indicating a diagnosis for dementia based on a standard code list in the QOF[7] (Supplementary Table 1). Additionally, we defined two further groups based on codes associated with dementia: "GP awareness", which is related to suspected memory impairment or other codes indicative of Dementia without a formal diagnosis of dementia (Supplementary Table 2); "GP administration", which refers to other administrative codes on the GP system relating to dementia (Supplementary table 3). "Any GP record" of dementia was based on the "GP diagnosis" category only, while the other categories were used to investigate recording patterns in patients identified as having dementia from their death certificate. To check whether length of registration prior to death had influenced recording, we carried out sensitivity analyses restricted to patients registered in their practice for at least a year before death.

Dementia recording on HES and ONS

Within the linked hospitalisations and mortality datasets we searched all records for evidence of a diagnosis of dementia, which are both coded using International Classification of Diseases version 10 (ICD-10) codes (Supplementary table 4). For

hospitalisations, HES Admitted Patient Care (HES APC) data are collected on all admissions to National Health Service (NHS) hospitals in England[16], with the primary reason for admission coded along with other major co-morbidities. Any recording of dementia was counted as evidence of a dementia diagnosis. For mortality, the ONS dataset extracts summary information from the Medical Certificate of the Cause of Death (MCCD), the document completed by a doctor involved in the care of the patient. It has two parts: conditions leading to death are recorded in Part 1 and other significant conditions contributing to the death are recorded in Part 2[10]. Any recording was counted as evidence of a dementia diagnosis, but we sometimes make the distinction between "listed as underlying cause" (Part 1 only) and "any mention" (Part 1 or 2).

Statistical Analyses

Prevalence estimates of dementia recording are reported in the text with 95% confidence intervals calculated from the proportion recorded. A visual summary of the overlap recorded in the three data sources (GP, HES records and ONS mortality statistics) was represented by Venn diagrams in 2001 and 2015, using approximate scaling for each to represent the percentage of deaths recorded in the three data sources. A fixed-sized rectangle borders the diagram and represents 100% of deaths in each year. The plots were carried out using the Venn Diagram Plotter freely available from the Pacific Northwest National Laboratory[20].

Results

Trends among all deaths

Table 1 and Supplementary Figure 1 summarise the trends in annual dementia recording in death certification, GP records and HES data in all deaths in the study population between 2001-2015. Between 2001 and 2015 there were a total of 207,068 deaths in the study population, of which 19,627 (9.5%) deaths had any mention of dementia (either as a contributory or underlying cause of death) on the death certificate. Dementia was listed as the underlying cause in 10,253 (5.0%) deaths. There was an increasing trend in dementia recording in records from all three data sources: death certification, electronic GP health records and HES data.

[Insert Table 1]

In the ONS data any mention of dementia on the death certificate over the study period tripled, from 5.3% (4.9 to 5.7%) to 15.4% (14.7 to 16.0%) whilst recording of dementia as the underlying cause of death increased from 2.7% (2.5 to 3.0%) to 10.0% (9.4 to 10.6%). Of deaths recorded as dementia on the death certificate, the proportion recording it as the underlying cause increased over this period from 51.3% (50.5 to 52.1%) to 65.0% (64.2 to 65.9%). GP recording of dementia on electronic GP health records increased from 7.8% (7.4 to 8.3%) of all deaths in 2001 to 21.2% (20.5 to 21.9%) in 2015. HES records showed a similar pattern of increase in coding of

196 dementia over the study period, with 7.8% (7.4 to 8.3%) of records including a
197 dementia code in 2001 increasing to 23.8% (23.0 to 24.5%) in 2015. When we limited
198 analyses to patients registered in their practice for at least a year, findings were similar
199 (Supplementary Table 5).
200 The triangulation of dementia recording from all 3 sources is shown in Figure 1 for
201 2001 and 2015. There was an increase in dementia recorded in any one of the data
202 sources, from 13.2% (12.7 to 13.8%) of all deaths with dementia recorded in 2001 to
203 28.6% (27.8 to 29.4%) of all deaths in 2015. In particular there was a substantial
204 increase in subjects with a dementia diagnosis from all 3 sources (grey area) rising
205 from 1.5% (1.3 to 1.7%) in 2001 to 10.4% (9.8 to 10.9%) in 2015.
206
207 However, relying on the death certificate alone for a diagnosis of dementia gives an
208 incomplete picture of the number of people in England dying with dementia (i.e. all
209 patients who die with a diagnosis of dementia from any source). While the percentage
210 of all deaths with a diagnosis recorded in any of GP, HES or ONS captured by death
211 certificates has risen from 40.2% in 2001 (5.3% of 13.2%), it is still only approximately
212 half (53.8% = 15.4%/28.6%) of these deaths in 2015 (Figure 1). Due to the increase in
213 GP and HES recording, this means the percentage of all deaths with a dementia
214 diagnosis recorded in GP or HES but not mentioned on the death certificate, has risen
215 from 7.9% to 13.3%.
216
217 [Insert Figure 1]
218
219

Trends among deaths with any mention of dementia on the death certificate

Figure 2 illustrates trends in dementia related recording in GP or HES records amongst patients with any mention of dementia on the death certificate (Supplementary Table 6 provides the underlying data). The proportion of patients who had a GP (red line) or HES (blue line) diagnosis shows a similar pattern of increase over this period. Together, this represents an increase from 76.3% to 95.7% in the percentage who had a prior diagnosis in GP and/or HES records. In addition, trends in codes indicating GP dementia awareness showed a steady increase over this period, while the use of GP administrative codes quickly increased once they were introduced with QOF circa 2006. Putting all these codes together, the percentage of deaths with dementia mentioned on the death certificate that also had supporting evidence in either GP and/or HES records rose from 77.2% in 2001 to 97.7% in 2015.

[Insert Figure 2]

Discussion

Summary of main findings

There is increased recording of dementia diagnoses across both primary and secondary care between 2001 and 2015, and this is reflected in an increased number of deaths recording dementia, both as a contributory or underlying cause, a trend also

seen in national data[3]. By 2015, the vast majority (97.7%) of deaths with dementia mentioned on the death certificate had existing evidence of dementia recorded in primary and/or secondary care records. However, over the same period, the percentage of people dying with dementia, but not of dementia has substantially increased. In particular, while the percentage of deaths with dementia mentioned on the death certificate, but not as underlying cause, has increased, this has not kept pace with the rise in dementia diagnoses in primary and secondary care records. Thus by 2015 only half of those dying with dementia have it mentioned on the death certificate as a contributory cause. While not surprising, it does mean that death certification provides an inadequate picture of the prevalence of dementia at the time of death.

Strengths and limitations

One of the major strengths of this study is the breadth of geographical coverage and basis in an unselected population from a large, validated longitudinal primary care database that is broadly representative of the population[14]. The time period assessed includes key dementia related policy changes to QOF[8] and in contrast to some other studies, we have restricted to practices that contributed data over the entire study period for consistency.

In addition to the comprehensive data linkage between the databases[14] HES has universal coverage in England, which is a key strength[16], although due to variation in quality of coding, data about co-morbidities such as dementia may be entered

inconsistently across sites. As well as issues with missing data HES does not include outpatient data so any patients with dementia who attended a dementia/memory assessment clinic will not have been coded in HES, though diagnoses from such letters should have been coded in primary care records and therefore included in CPRD. HES-CPRD data first became available from April 1997[16], which may impact on the results as deaths from earlier in the study period would have a maximum of three years of prior hospital data. The time period assessed includes policy change related to hospital recording of dementia introduced in 2012[12].

We were constrained to using data for England only, as CPRD linkage to HES and ONS is limited to this area[15]. Data quality in CPRD is reliant on accurate coding by primary care staff and there may be variability in coding across sites, as well as issues with the Read codes associated with dementia as coding changes were introduced during the study period. This is illustrated by the sharp increase in recorded GP dementia awareness after 2006 which corresponded with the introduction of new dementia related codes incentivising QOF after 2006[7,8]. There was also a coding change affecting ONS records in 2010, with a modification in the rules on death certification, aimed at improving the accuracy of recording of the underlying cause of death. Whilst this did not impact greatly on the all-cause dementia rates (Supplementary Figure 2), it has affected the subtypes of dementia recorded, as a correction was made to the coding of vascular dementia and previously coded cerebrovascular disease was corrected to vascular dementia[21]. As a result of these coding changes there may have been some changes in the proportions of underlying cause within the any-mention of dementia group at the 2010 to 2011 transition. After this coding change

292 the number of deaths with any mention of dementia on the death certificate
293 continued to rise.
294
295
296 *Comparison with other studies*
297
298 A recent systematic review[23] of the validity of dementia diagnoses in routinely
299 collected UK electronic health records reported generally high validity, although
300 without providing a summary validity estimate. Individual studies have also previously
301 addressed recording of dementia across different data sources. Brown et al found
302 higher levels of agreement between GP and HES data (95%) than we reported, but in
303 a small sample of women only (n=340)[24]. Perera et al linked dementia diagnoses
304 from a London mental health database to ONS mortality data from 2006-2013 and
305 reported an increase in dementia recording over this period, consistent with our
306 findings[25]. A much larger study (47,386 people with dementia) examined the
307 diagnostic validity of dementia in CPRD records from 1998-2010, also using HES and
308 ONS records, as we did[26]. Whilst not directly comparable to our study, as they did
309 not examine trends over time and we provide more recent data; they found that 8%
310 had evidence of a dementia diagnosis across all three sources during this period,
311 compared to our figures of 1.5% in 2001 and 10.4% in 2015[26].
312
313 In UK, the Cognitive Functioning in Ageing Study (CFAS) provided important data on
314 trends over time (1989-2016), in accuracy of death certification of dementia, from
315 their large cohort study of patients aged >65 years (n=26,699)[4,27]. They

316 demonstrated an increase in overall unadjusted prevalence of dementia on death
317 certificates (5.3% to 25.9%) and an increase in sensitivity of dementia reporting on
318 death certificates compared to a gold-standard of study clinical diagnosis of dementia
319 (from 21% in CFAS I to 45.2% in CFAS II)[4,27]. These are consistent with our findings,
320 indicating a similar trend of increased recording of dementia on death certificates, but
321 with a recognition that death certificates still give an inadequate picture of the
322 number of people dying with dementia.
323
324 It is not generally well understood what influences decisions regarding diagnoses
325 recorded in the death certificate[28]. During our study period we observed a steady
326 increase in dementia appearing on death certificates between 2000-2015, while at the
327 same time age-specific incidence rates of dementia were falling in the UK[27]. This
328 trend has been replicated in other cohort studies in Europe and North America,
329 suggesting that over the last 25 years the incidence rate may have declined by 13%
330 per decade[29]. It seems plausible that the improvements in the management of
331 cardiovascular disease over time has contributed to this reduction, particularly for
332 vascular dementia[30]. This might also result in a deferral of dementia to older age,
333 however with people living longer, age at death will have increased over this time too,
334 so the likelihood of having dementia by the time of death would almost certainly have
335 risen as well. This could explain the increasing numbers of deaths from dementia
336 observed in this study. Other potential contributing factors over the study period
337 could include the increased public and medical awareness due to activity by
338 campaigning groups and government, as well as increased referral access to memory
339 clinics. The National Dementia Strategy, launched in 2009, has previously been shown

to be associated with a significant increase in dementia diagnosis rates and prescriptions of antidementia drugs[31]. Dementia deaths in this study with a prior diagnosis of dementia in both electronic GP and hospital records has increased from 76.3% in 2001 to 95.7% in 2015 which may reflect a change in clinicians' attitudes and less reluctance in entering a diagnosis of dementia due to concerns about stigma and increased case finding and confidence in management[32].

Implications for practice and public health policy

Changes in QOF in primary care and in policy relating to hospital inpatients, both designed to increase the diagnosis rate of dementia, have led to a greater awareness of dementia in clinical practice and increased recording of dementia on death certificates as a primary or contributory cause. Nevertheless, only half of those dying with a prior diagnosis of dementia had dementia recorded on their death certificate in 2015. The high and increasing proportion of people recognized to be dying "with" dementia (in addition to those dying "of" dementia) has important cost and workforce implications for both health and social care service planning for care of older people.

Further work

The introduction of Independent Medical Examiners (IME) from April 2019[33] could impact on dementia recording rates, as the role of the IME extends to discussions with relatives before deciding on cause of death. Repeating the study in the future and comparing it to current findings may give further insights into dementia detection and

recording in primary care. Previous work has demonstrated significant regional variations in dementia recording[34] this could also be investigated as a potential explanatory factor.

Conclusions

Our study demonstrates that between 2001 to 2015 in England, dementia recording in GP electronic records, hospital records and death certification increased. By 2015 the vast majority of deaths mentioning dementia on the death certificate had prior evidence of diagnosis in primary and/or secondary care (97.7%); a marked improvement from 2001. It emphasizes that when dementia is mentioned on death certificates there is good evidence backing this up. However, death certificates still give an inadequate picture of the total number of people dying with dementia; in 2015 only half of those people dying with dementia had dementia recorded on their death certificates.

Abbreviations

CFAS = Cognitive Functioning in Ageing Study

CPRD = Clinical Practice Research Datalink

DIS = Dementia Identification Scheme

DES = Directed Enhances Services

GP = General Practice

HES = Hospital Episode Statistics

ICD = International Classification of Diseases

IME = Independent Medical Examiners

MCCD = Medical Certificate of the Cause of Death

NHS = National Health Service

ONS = Office for National Statistics

QOF = Quality and Outcomes Framework

Declarations

Ethics approval and consent to participate

Access to CPRD data is subject to protocol approval by an Independent Scientific Advisory Committee (ISAC), Medicines and Healthcare Products Regulatory Agency, London, UK. The main study protocol was approved in May 2017 (ISAC Protocol17_031R).

Consent for publication

Not applicable

Availability of data and materials

The data that support the findings of this study are available from CPRD but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available.

Competing interests

The authors declare that they have no competing interests

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None

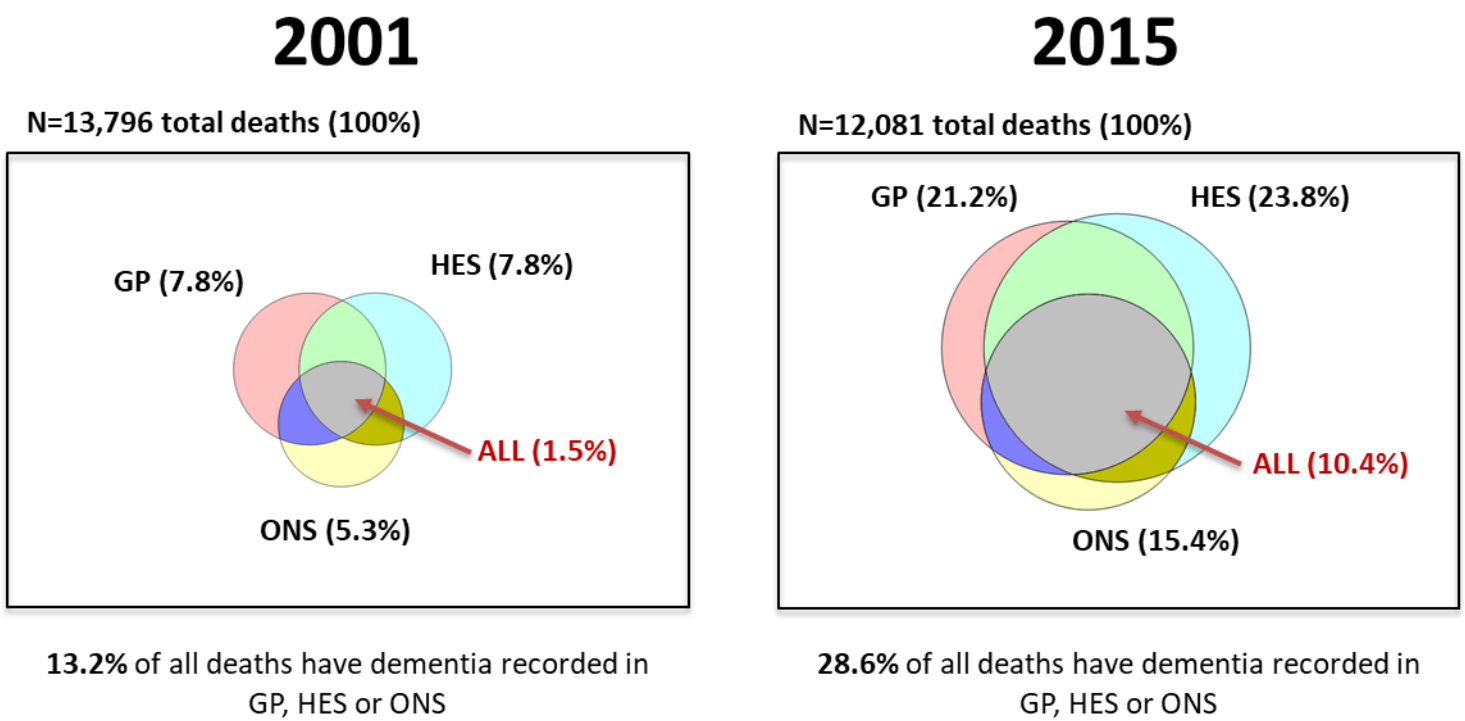
Authors' contributions

SA, IC, TH, SD, DG and DS all contributed to the design and concept of the study, interpretation of the data, and writing the manuscript. IC carried out the data extractions and analysis. All authors have read and approved the final version of the manuscript.

Acknowledgments

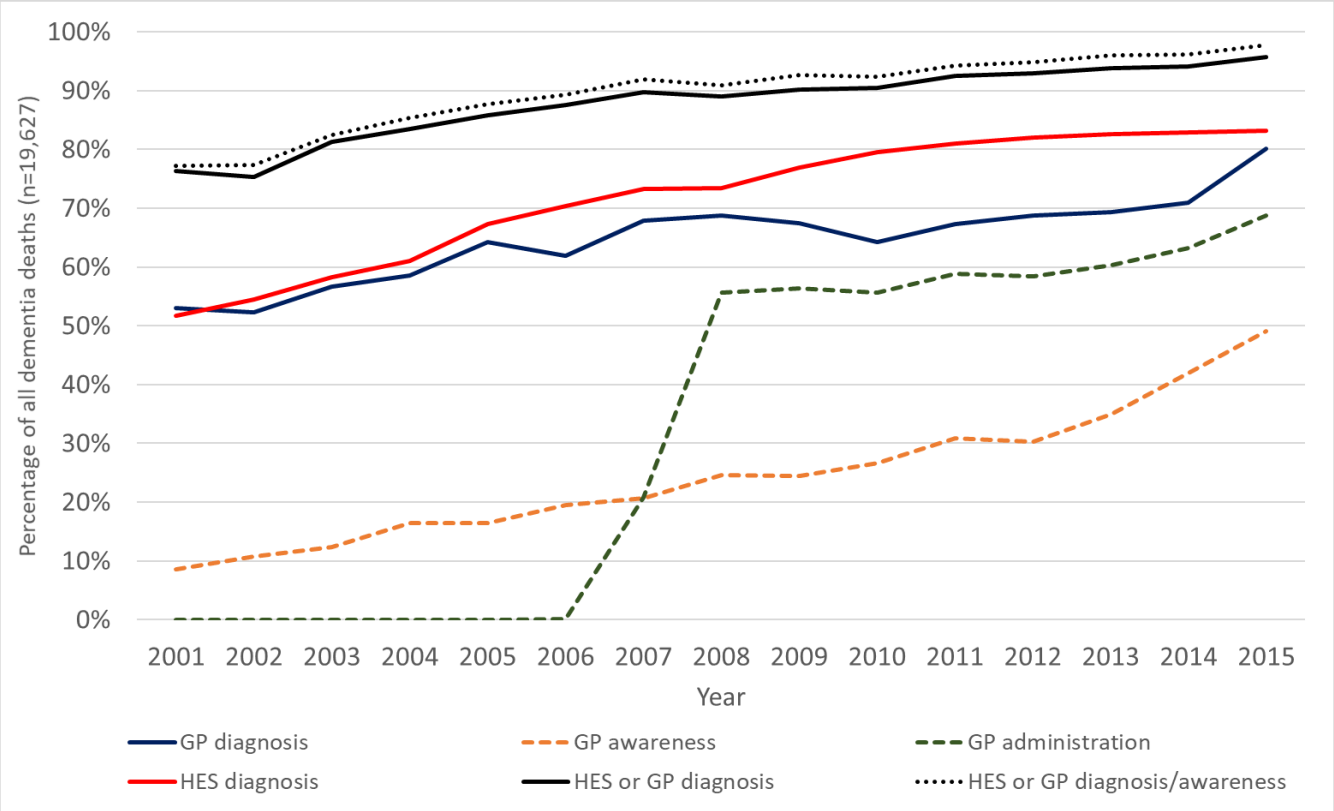
Not applicable

Figure 1: Triangulation of GP, HES and ONS recording of dementia in 2015 vs 2001 for all deaths



Footnote: All %'s are percentages of all deaths from any cause; (i) for GP(diagnostic codes), (ii) for HES (diagnostic codes) and (iii) for ONS (any mention of dementia on death certificate)

Figure 2: Trends in the recording of dementia diagnoses and other information in GP and HES among all death certifications with mention of dementia 2001-2015 (n=19,627)



Footnote: Definition of Categories: GP diagnosis = includes specific Read codes indicating a diagnosis for dementia, GP awareness = includes Read codes related to suspected memory impairment or other codes indicative of Dementia, GP administration = Other administrative codes on GP system relating to dementia, Any GP recording = Any of GP diagnosis, awareness or administration, HES diagnosis = refers to admission records which mention dementia either as primary cause of admission or other

1 **Table 1: Summary of dementia recording among all deaths from 2001-2015 (n=207,068)**

2

Year of Death	Total Deaths	Dementia recording on Death Certificate					Prior Dementia diagnosis in GP or HES records							
		Any mention		Listed as underlying cause only			GP diagnosis		HES diagnosis		GP or HES diagnosis plus death certificate		GP or HES diagnosis but not on death certificate	
	n	n	% of total deaths	n	% of total deaths	% of dementia deaths only*	n	% of total deaths	n	% of total deaths	n	% of total deaths	n	% of total deaths
2001	13,796	733	5.3%	376	2.7%	51.3%	1,077	7.8%	1,079	7.8%	1,651	12.0%	1,092	7.9%
2002	14,099	820	5.8%	387	2.7%	47.2%	1,242	8.8%	1,322	9.4%	1,898	13.5%	1,280	9.1%
2003	14,386	919	6.4%	403	2.8%	43.9%	1,375	9.6%	1,470	10.2%	2,105	14.6%	1,358	9.4%
2004	13,997	927	6.6%	398	2.8%	42.9%	1,367	9.8%	1,515	10.8%	2,090	14.9%	1,316	9.4%
2005	13,863	968	7.0%	419	3.0%	43.3%	1,399	10.1%	1,635	11.8%	2,130	15.4%	1,299	9.4%

2006	13,790	1,014	7.4%	414	3.0%	40.8%	1,420	10.3%	1,705	12.4%	2,196	15.9%	1,309	9.5%
2007	13,753	1,087	7.9%	451	3.3%	41.5%	1,602	11.6%	1,886	13.7%	2,361	17.2%	1,386	10.1%
2008	14,163	1,287	9.1%	525	3.7%	40.8%	1,802	12.7%	2,169	15.3%	2,653	18.7%	1,507	10.6%
2009	13,562	1,374	10.1%	547	4.0%	39.8%	1,768	13.0%	2,276	16.8%	2,710	20.0%	1,472	10.9%
2010	13,921	1,478	10.6%	580	4.2%	39.2%	1,859	13.4%	2,486	17.9%	2,899	20.8%	1,562	11.2%
2011	13,607	1,565	11.5%	988	7.3%	63.1%	1,931	14.2%	2,643	19.4%	3,035	22.3%	1,588	11.7%
2012	14,058	1,823	13.0%	1,149	8.2%	63.0%	2,150	15.3%	2,954	21.0%	3,369	24.0%	1,675	11.9%
2013	14,274	1,868	13.1%	1,160	8.1%	62.1%	2,307	16.2%	3,026	21.2%	3,469	24.3%	1,716	12.0%
2014	13,718	1,909	13.9%	1,250	9.1%	65.5%	2,394	17.5%	3,075	22.4%	3,665	26.7%	1,756	12.8%
2015	12,081	1,855	15.4%	1,206	10.0%	65.0%	2,562	21.2%	2,870	23.8%	3,381	28.0%	1,605	13.3%
All	207,068	19,627	9.5%	10,253	5.0%	52.2%	26,255	12.7%	32,111	15.5%	39,612	19.1%	21,921	10.6%

* - Denominator here is all deaths with any mention of dementia on death certificate

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Supplementary Table 1: Read codes indicating dementia diagnosis on GP record ("GP diagnosis")

Readcode	Description
1461.00	H/O: dementia
3AE3.00	GDS level 4 - moderate cognitive decline
3AE4.00	GDS level 5 - moderately severe cognitive decline
3AE5.00	GDS level 6 - severe cognitive decline
3AE6.00	GDS level 7 - very severe cognitive decline
E00..00	Senile and presenile organic psychotic conditions
E00..11	Senile dementia
E00..12	Senile/presenile dementia
E000.00	Uncomplicated senile dementia
E001.00	Presenile dementia
E001000	Uncomplicated presenile dementia
E001100	Presenile dementia with delirium
E001200	Presenile dementia with paranoia
E001300	Presenile dementia with depression
E001z00	Presenile dementia NOS
E002.00	Senile dementia with depressive or paranoid features
E002000	Senile dementia with paranoia
E002100	Senile dementia with depression
E002z00	Senile dementia with depressive or paranoid features NOS
E003.00	Senile dementia with delirium
E004.00	Arteriosclerotic dementia
E004.11	Multi infarct dementia
E004000	Uncomplicated arteriosclerotic dementia
E004100	Arteriosclerotic dementia with delirium
E004200	Arteriosclerotic dementia with paranoia
E004300	Arteriosclerotic dementia with depression
E004z00	Arteriosclerotic dementia NOS
E00y.00	Other senile and presenile organic psychoses
E00y.11	Presbyophrenic psychosis
E00z.00	Senile or presenile psychoses NOS
E012.00	Other alcoholic dementia
E012.11	Alcoholic dementia NOS
E012000	Chronic alcoholic brain syndrome
E02y100	Drug-induced dementia
E041.00	Dementia in conditions EC
Eu00.00	[X]Dementia in Alzheimer's disease
Eu00000	[X]Dementia in Alzheimer's disease with early onset
Eu00011	[X]Presenile dementia,, Alzheimer's type
Eu00012	[X]Primary degenerative dementia, Alzheimer's type, presenile onset
Eu00013	[X]Alzheimer's disease type 2
Eu00100	[X]Dementia in Alzheimer's disease with late onset
Eu00111	[X]Alzheimer's disease type 1
Eu00112	[X]Senile dementia,,Alzheimer's type
Eu00113	[X]Primary degenerative dementia of Alzheimer's type, senile onset
Eu00200	[X]Dementia in Alzheimer's dis, atypical or mixed type
Eu00z00	[X]Dementia in Alzheimer's disease, unspecified
Eu00z11	[X]Alzheimer's dementia unspecified
Eu01.00	[X]Vascular dementia
Eu01.11	[X]Arteriosclerotic dementia
Eu01000	[X]Vascular dementia of acute onset

Readcode	Description
Eu01100	[X]Multi-infarct dementia
Eu01111	[X]Predominantly cortical dementia
Eu01200	[X]Subcortical vascular dementia
Eu01300	[X]Mixed cortical and subcortical vascular dementia
Eu01y00	[X]Other vascular dementia
Eu01z00	[X]Vascular dementia, unspecified
Eu02.00	[X]Dementia in other diseases classified elsewhere
Eu02000	[X]Dementia in Pick's disease
Eu02100	[X]Dementia in Creutzfeldt-Jakob disease
Eu02200	[X]Dementia in Huntington's disease
Eu02300	[X]Dementia in Parkinson's disease
Eu02400	[X]Dementia in human immunodeficiency virus [HIV] disease
Eu02500	[X]Lewy body dementia
Eu02y00	[X]Dementia in other specified diseases classified elsewhere
Eu02z00	[X] Unspecified dementia
Eu02z11	[X] Presenile dementia NOS
Eu02z12	[X] Presenile psychosis NOS
Eu02z13	[X] Primary degenerative dementia NOS
Eu02z14	[X] Senile dementia NOS
Eu02z15	[X] Senile psychosis NOS
Eu02z16	[X] Senile dementia, depressed or paranoid type
Eu04100	[X]Delirium superimposed on dementia
F110.00	Alzheimer's disease
F110000	Alzheimer's disease with early onset
F110100	Alzheimer's disease with late onset
F111.00	Pick's disease
F112.00	Senile degeneration of brain
F116.00	Lewy body disease

Supplementary Table 2: Read codes indicating that GP has concern regarding dementia ("GP awareness")

Readcode	Description
14Od.00	At risk of dementia
1B1A.00	Memory loss - amnesia
1B1A.11	Amnesia symptom
1B1A.12	Memory loss symptom
1B1A.13	Memory disturbance
1B1A000	Temporary loss of memory
1B1A100	Short-term memory loss
1S23.00	Memory impairment
1JA2.00	Suspected dementia
38C1000	Assessment for dementia
3A...12	Dementia assessment
3A10.00	Memory: own age not known
3A20.00	Memory: present time not known
3A30.00	Memory: present place not known
3A40.00	Memory: present year not known
3A50.00	Memory: own DOB not known
3A60.00	Memory: present month not known
3A70.00	Memory: important event not known
3A80.00	Memory: important .person not known
3A91.00	Memory: count down unsuccess.
3AA1.00	Memory: address recall unsuccesful
3AD..00	Dementia test
3AD1.00	Ten item dementia test
3AD2.00	Thirty seven item dementia test
3AD3.00	Six item cognitive impairment test
3AE..00	Global deterioration scale: assessment of primary degenerative dementia
3AE2.00	GDS level 3 - mild cognitive decline
7P10400	Neuropsychology test of memory
8HTY.00	Referral to memory clinic
8IAe000	Dementia advance care plan declined
8IAe200	Dementia advance care plan review declined
8IBB000	Dementia assessment not indicated
8IEn.00	Referral to memory clinic declined
8T05200	Referral for dementia assessment
9Nk1.00	Seen in memory clinic
9OqD.00	Dementia screening questionnaire sent to patient
9OqE.00	Dementia screening questionnaire completed
9OqF.00	No response to dementia screening invitation
E2A1000	Mild memory disturbance
E2A1100	Organic memory impairment
R00z011	[D]Memory deficit
Z7CE400	Memory disturbance (& amnesia (& symptom))
Z7CE412	Memory loss symptom
Z7CE413	Memory loss - amnesia
Z7CE414	Memory disturbance
Z7CE415	Loss of memory
Z7CE500	Forgetful
Z7CE600	Amnesia
Z7CE611	Memory loss
Z7CE612	Memory gone
Z7CE613	Dysmnesia
Z7CE614	Memory loss - amnesia

Readcode	Description
Z7CE615	Loss of memory
Z7CE616	LOM - Loss of memory
Z7CEA12	Impairment of immediate recall
Z7CEC11	Loss of memory for recent events
Z7CEC12	No memory for recent events
Z7CED00	Amnesia for day to day facts
Z7CEE00	Amnesia for important personal information
Z7CEH00	Memory impairment
Z7CEH11	Memory dysfunction
Z7CEH12	Memory deficit
Z7CEH14	Memory problem
Z7CEH15	Poor memory
Z7CEJ00	Memory lapses
Z7CEK00	Minor memory lapses
Z7CEL00	Mild memory disturbance
Z7CEN00	Confabulation
Z7CEN11	Invents experiences to compensate for loss of memory
Z7CEO00	Momentary confabulation
Z7CEP00	Fantastical confabulation
Z7CF.00	Observations of memory performance
Z7CF100	Memory recall normal
Z7CF111	Global memory recall within normal limits
Z7CF300	Immediate recall observations
Z7CF400	Digit span performance
Z7CF500	Digit span forwards
Z7CF700	Short-term memory within normal limits
Z7CF711	Good short-term memory
Z7CF712	No problem with short-term memory
Z7CF800	Poor short-term memory
Z7CF811	Short-term memory loss
Z7CF900	Able to recall random address at five minutes
Z7CFA00	Unable to recall random address at five minutes
Z7CFC00	Unable to recall five digit number at five minutes
Z7CFF00	Forgets what was going to do
Z7CFG00	Forgets what was going to say
Z7CFH00	Forgets recent activities
Z7CFI00	Forgets what has just done
Z7CFJ00	Forgets what has just said
Z7CFK00	Forgets what has just read
Z7CFL00	Forgets what has just seen
Z7CFM00	Forgets what has just heard
Z7CFO00	Poor long-term memory
Z7CFO11	Long-term memory loss
Z7CFQ00	Unable to remember own date of birth
Z7CFS00	Unable to remember own age
Z7CFS11	Cannot remember own age
Z7CFU00	Unable to remember day of the week
Z7CFW00	Unable to remember today's date
Z7CFa00	Unable to remember current year
Z7CFe00	Unable to remember name of current prime minister
Z7CFg00	Cannot remember names of intimates
Z7CFh00	Cannot remember birth dates of children
Z7CFi00	Cannot remember wedding anniversary
Z7CFq00	Unable to remember motor skills
Z7CFs00	Unable to remember new motor skills
Z7CFw00	Memory aided by use of diary

Readcode	Description
Z7CFx00	Memory aided by use of labels
Z7CFz00	Memory aided by use of lists
ZR3V.00	Clinical dementia rating scale
ZR3V.11	DRS - Clinical dementia rating scale
ZR3V.12	CDR - Clinical dementia rating scale
ZR3V.13	Dementia rating scale
ZRV9.00	Kendrick battery for detection of dementia in the elderly
ZRV9.11	Kendrick cognitive tests for the elderly

Supplementary Table 3: Read codes for GP related dementia administration ("GP administration")

Readcode	Description
38C1300	Assessment of psychotic and behavioural symptoms of dementia
66h..00	Dementia monitoring
6AB..00	Dementia annual review
8BM0200	Dementia medication review
8BPa.00	Antipsychotic drug therapy for dementia
8CMZ.00	Dementia care plan
8CMZ000	Dementia care plan agreed
8CMZ100	Dementia care plan reviewed
8CMZ200	Dementia care plan declined
8Hla.00	Referral to dementia care advisor
8T05.00	Referral to dementia service
8T05000	Referral to dementia support organisation
8T05100	Referral to dementia support organisation declined
9Ou..00	Dementia monitoring administration
9Ou1.00	Dementia monitoring first letter
9Ou2.00	Dementia monitoring second letter
9Ou3.00	Dementia monitoring third letter
9Ou4.00	Dementia monitoring verbal invite
9Ou5.00	Dementia monitoring telephone invite
9hD..00	Exception reporting: dementia quality indicators
9hD0.00	Excepted from dementia quality indicators: Patient unsuitable
9hD1.00	Excepted from dementia quality indicators: Informed dissent

Supplementary Table 4: ICD-10 for dementia recording in HES and ONS datasets

ICD-10 Code	Description
F00*	Dementia in Alzheimer's disease
F01*	Vascular dementia
F02*	Dementia in other diseases classified elsewhere
F03*	Unspecified dementia
G30*	Alzheimer's disease

*Note: All sub-codes included

Supplementary Table 5: Summary of dementia recording among all deaths from 2001-2015 (n=207,068) – One Year Registration Only

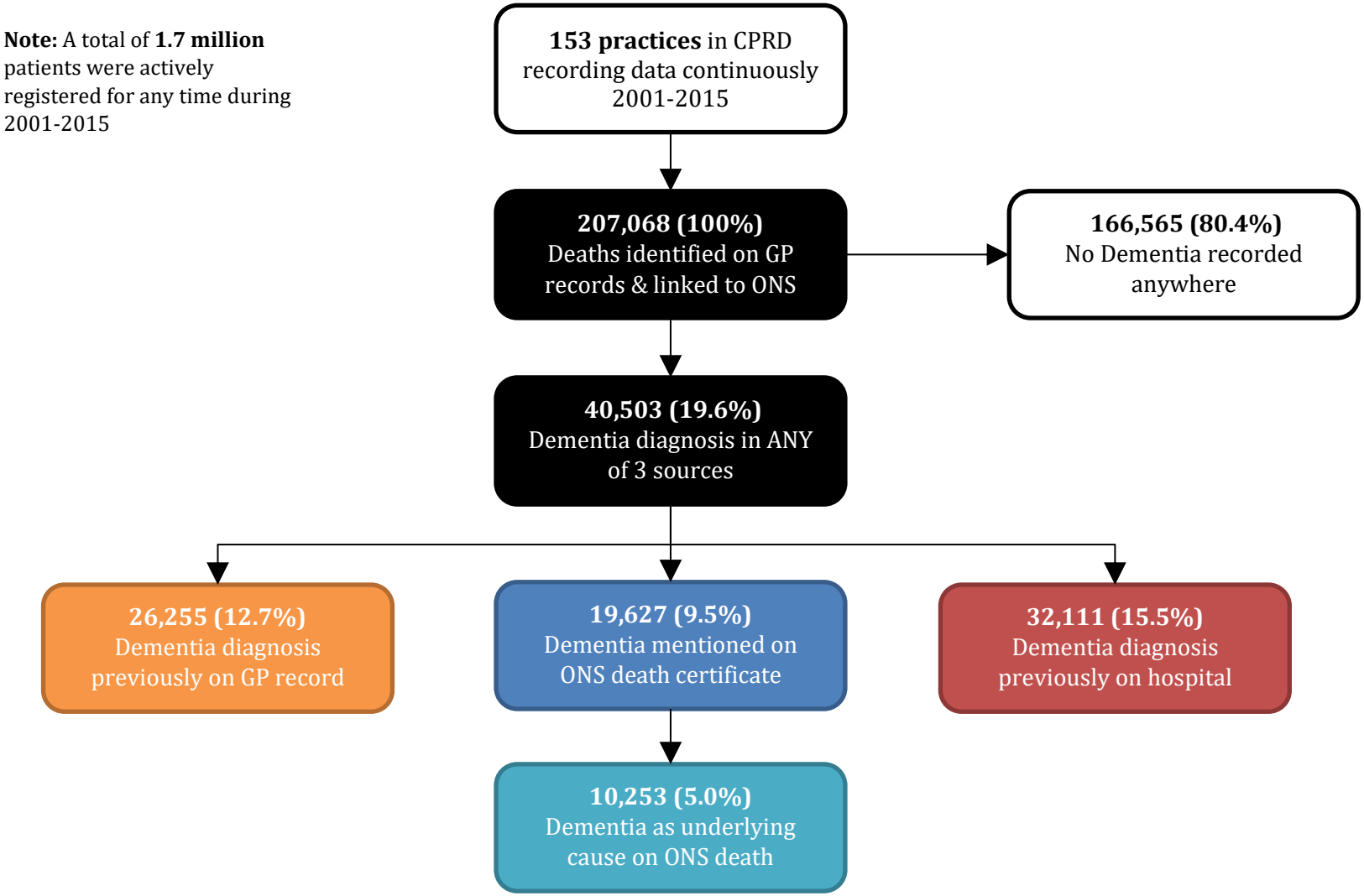
Year of Death	Total Deaths	Dementia recording on Death Certificate					Prior Dementia diagnosis in GP or HES records							
		Any mention		Listed as underlying cause only			GP diagnosis		HES diagnosis		GP or HES diagnosis plus death certificate		GP or HES diagnosis but not on death certificate	
	n	n	% of total deaths	n	% of total deaths	% of dementia deaths only*	n	% of total deaths	n	% of total deaths	n	% of total deaths	n	% of total deaths
2001	12,311	277	**2.3%**	274	**2.2%**	**50.3%**	551	**4.5%**	863	**7.0%**	811	**6.6%**	1,281	**10.4%**
2002	12,567	306	**2.4%**	341	**2.7%**	**47.3%**	647	**5.1%**	1,001	**8.0%**	1,036	**8.2%**	1,512	**12.0%**
2003	12,779	302	**2.4%**	385	**3.0%**	**44.0%**	687	**5.4%**	1,096	**8.6%**	1,143	**8.9%**	1,654	**12.9%**
2004	12,320	289	**2.3%**	385	**3.1%**	**42.9%**	674	**5.5%**	1,062	**8.6%**	1,141	**9.3%**	1,592	**12.9%**
2005	12,296	313	**2.5%**	411	**3.3%**	**43.2%**	724	**5.9%**	1,118	**9.1%**	1,270	**10.3%**	1,679	**13.7%**
2006	12,185	307	**2.5%**	455	**3.7%**	**40.3%**	762	**6.3%**	1,112	**9.1%**	1,276	**10.5%**	1,670	**13.7%**
2007	12,190	348	**2.9%**	487	**4.0%**	**41.7%**	835	**6.8%**	1,287	**10.6%**	1,454	**11.9%**	1,856	**15.2%**
2008	12,473	414	**3.3%**	569	**4.6%**	**42.1%**	983	**7.9%**	1,426	**11.4%**	1,671	**13.4%**	2,059	**16.5%**
2009	11,925	412	**3.5%**	619	**5.2%**	**40.0%**	1,031	**8.6%**	1,420	**11.9%**	1,761	**14.8%**	2,126	**17.8%**
2010	12,160	454	**3.7%**	682	**5.6%**	**40.0%**	1,136	**9.3%**	1,493	**12.3%**	1,928	**15.9%**	2,266	**18.6%**
2011	11,774	755	**6.4%**	439	**3.7%**	**63.2%**	1,194	**10.1%**	1,536	**13.0%**	2,017	**17.1%**	2,345	**19.9%**
2012	12,224	886	**7.2%**	513	**4.2%**	**48.6%**	1,823	**14.9%**	1,741	**14.2%**	2,294	**18.8%**	2,643	**21.6%**
2013	12,321	874	**7.1%**	534	**4.3%**	**62.1%**	1,408	**11.4%**	1,846	**15.0%**	2,339	**19.0%**	2,693	**21.9%**
2014	11,795	952	**8.1%**	491	**4.2%**	**49.9%**	1,909	**16.2%**	1,925	**16.3%**	2,352	**19.9%**	2,750	**23.3%**
2015	10,348	898	**8.7%**	477	**4.6%**	**48.4%**	1,855	**17.9%**	2,014	**19.5%**	2,156	**20.8%**	2,561	**24.7%**
All	181,668	7,787	**4.3%**	7,062	**3.9%**	**48.0%**	16,219	**8.9%**	20,940	**11.5%**	24,649	**13.6%**	30,687	**16.9%**

* - Denominator is all deaths with any mention of dementia on death certificate
** - Denominator is all deaths with any mention of dementia on GP or HES record

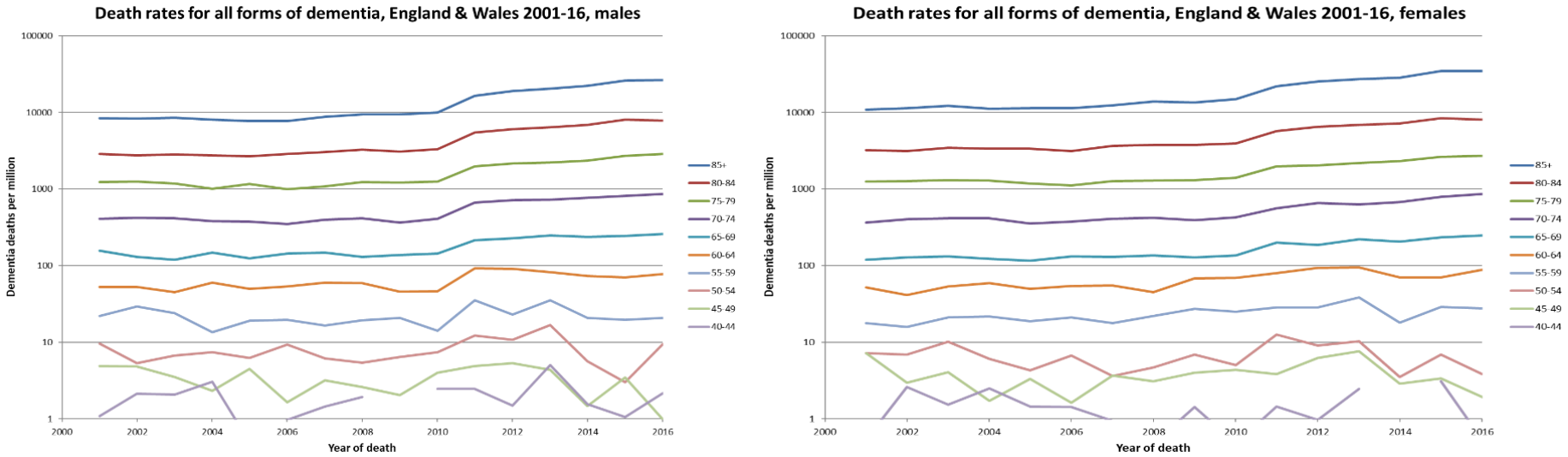
Supplementary Table 6: Summary of dementia recording in GP and HES among all deaths certified with mention of dementia from 2001 to 2015 (n=19,627)

Year of Death	All deaths mentioning dementia	Has prior GP diagnosis		Has prior HES diagnosis		Has prior diagnosis (GP or HES)		Has prior GP diagnosis other GP information suggestive of dementia		Has prior diagnosis (GP or HES) or other GP information suggestive of dementia	
	n	n	%	n	%	n	%	n	%	n	%
2001	733	389	**53.1%**	379	**51.7%**	559	**76.3%**	564	**76.9%**	566	**77.2%**
2002	820	429	**52.3%**	447	**54.5%**	618	**75.4%**	631	**77.0%**	634	**77.3%**
2003	919	520	**56.6%**	536	**58.3%**	747	**81.3%**	755	**82.2%**	758	**82.5%**
2004	927	543	**58.6%**	566	**61.1%**	774	**83.5%**	789	**85.1%**	791	**85.3%**
2005	968	622	**64.3%**	651	**67.3%**	831	**85.8%**	847	**87.5%**	849	**87.7%**
2006	1,014	627	**61.8%**	714	**70.4%**	887	**87.5%**	903	**89.1%**	906	**89.3%**
2007	1,087	738	**67.9%**	796	**73.2%**	975	**89.7%**	997	**91.7%**	999	**91.9%**
2008	1,287	885	**68.8%**	945	**73.4%**	1,146	**89.0%**	1,159	**90.1%**	1,170	**90.9%**
2009	1,374	927	**67.5%**	1,057	**76.9%**	1,238	**90.1%**	1,266	**92.1%**	1,273	**92.6%**
2010	1,478	950	**64.3%**	1,175	**79.5%**	1,337	**90.5%**	1,362	**92.2%**	1,366	**92.4%**
2011	1,565	1,052	**67.2%**	1,267	**81.0%**	1,447	**92.5%**	1,471	**94.0%**	1,475	**94.2%**
2012	1,823	1,252	**68.7%**	1,494	**82.0%**	1,694	**92.9%**	1,722	**94.5%**	1,730	**94.9%**
2013	1,868	1,295	**69.3%**	1,543	**82.6%**	1,753	**93.8%**	1,786	**95.6%**	1,792	**95.9%**
2014	1,909	1,355	**71.0%**	1,582	**82.9%**	1,797	**94.1%**	1,832	**96.0%**	1,836	**96.2%**
2015	1,855	1,487	**80.2%**	1,544	**83.2%**	1,776	**95.7%**	1,805	**97.3%**	1,813	**97.7%**
All	19,627	13,071	**66.6%**	14,696	**74.9%**	17,579	**89.6%**	17,889	**91.1%**	17,958	**91.5%**

Supplementary Figure 1: Summary of death recording by source in all deaths identified from CPRD database between 2001 and 2015



Supplementary Figure 2: Death rate for all forms of dementia, England and Wales 2001 to 2016 for males and females



Footnotes:
1. These figures are based on data from the Office for National Statistics historical mortality datasets and have been plotted on a log scale
2. Restricted to ICD-10 (2001 onwards)
3. Coding changes occurred in 2001-02 (affecting vascular dementia mainly) and 2010-11 (affecting vascular and other specified forms of dementia much more than Alzheimer's or unspecified)